

Chronic Pain

A short guide to chronic pain and how to get the support you need

Brain & Spine Foundation

in collaboration with



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Introduction

If you are one of the millions of people in the UK living with chronic pain, it is important to know that **you are not alone**.

There is support for you that can help you to manage your pain and reduce the impact it has on your life.

This short guide is intended to help you:

- understand what chronic pain is
- get the support you need
- learn about what therapies are available

Do you have a question or need more support to make sense of the information in this leaflet?

Talk to one of the neuroscience nurses on our helpline on **0808 808 1000** (Mon-Fri, 9am-4pm) or via email at <u>helpline@brainandspine.org.uk</u>

You are not alone

Living with chronic pain is not easy and it can sometimes feel very lonely and isolating. It is OK to experience these feelings, but we want you to know that you're not alone.

It is estimated that between 1 in 3 and 1 in 2 people are affected by chronic pain in the UK.

| In the UK, between | | | 28 million |
|---------------------------|-----|---|--------------|
| one person in every three | ••• | | people |
| and | | = | living with |
| one person in every two | • | | chronic pain |

Some people call chronic pain an 'invisible illness,' as you cannot tell if someone is affected just by looking at them.

Speaking to other people who are living with chronic pain can give you the chance to listen to their stories and share your own. You can find details of support groups and other organisations at the end of this leaflet.

You may also want to share this leaflet with your family and friends to help them understand more about what you are experiencing.



What is chronic pain?

Chronic pain, also called persistent or long-term pain, is:

- pain that lasts for 12 weeks (three months) or more, or
- pain that continues after you have recovered from an injury or illness

Our current understanding of chronic pain is that there are changes to how our bodies send and respond to pain signals, and this affects our experience of pain. This can include sending signals when there is no injury or illness.

This is different to other types of pain where there is usually a clear injury or illness that causes the pain signals and can explain the level of pain we are experiencing.

Types of pain

Whilst this leaflet focuses on chronic pain, other types of pain exist. Pain can be divided in to different types based on:

Length of time

Acute pain Pain that only lasts for a short time and then goes away after you have healed or recovered

Chronic pain

Pain that lasts for 12 weeks or more, or past the point of recovery

Intermittent pain Pain that starts and stops with pain-free periods between each episode

Cause of your pain

Nociceptive pain Pain that is caused by an injury or illness affecting your body

Neuropathic pain Pain that is caused by damage to your brain, spinal cord, or nerves

Cancer-related pain Pain that is caused by the effects of

cancer or the treatments for cancer on your body

Your GP will help you to diagnose your pain correctly and make sure you are receiving the right support to manage it.

What causes chronic pain?

Chronic pain has many possible causes. It affects people of all ages and can occur anywhere in the body.

Chronic pain can be a symptom of another condition or long-term health problem such as endometriosis, ulcerative colitis, or arthritis.

Chronic pain can develop following an injury, illness, or surgery.

Sometimes, chronic pain may be experienced without any known cause.

Depending on whether your pain is related to or caused by another condition, it may be defined as either:

- chronic primary pain, or
- chronic secondary pain

Chronic primary pain is chronic pain that is not related to a separate underlying condition.

Chronic primary pain includes chronic pain conditions such as fibromyalgia or chronic low back pain, where the condition itself is defined by having chronic pain.

Chronic pain that is related to or caused by a separate underlying condition is called **chronic secondary pain**.

It is possible to have both chronic primary pain and chronic secondary pain at the same time.

The following are just some of the many different chronic pain conditions that can affect people:

- **Fibromyalgia** a chronic pain condition that causes widespread pain all over the body, and can also cause fatigue, headaches, muscle stiffness, and difficulties with sleeping and concentrating.
- **Chronic migraine** a type of headache that lasts at least 15 days a month, for more than 12 weeks, and where for least 8 of those days you also experience migraine features, such as throbbing pain, dizziness, and sensitivity to light and sound.
- Chronic low back pain pain in the lower area of the back (below the ribcage) and waist that carries on for more than 12 weeks or continues after you have recovered from an injury or illness. You may also be stiff and have difficulty moving and standing straight.
- Complex Regional Pain Syndrome (CRPS) a chronic pain condition in which you might experience severe ongoing pain in a specific part of your body, such as one of your arms or legs. This often follows an injury to that part of your body.
- Persistent Spinal Pain Syndrome Type 2 (PSPS-T2) a chronic pain condition in which you experience new or ongoing pain after having spinal surgery for back or leg pain. This can include pain that may have been reduced by the surgery but is still present.

We know that there are many more chronic pain conditions than we have listed here.

Please **visit** <u>our website</u> to find information and support for other conditions that are not listed here.



How might chronic pain be affecting you?

Everyone's experience of chronic pain is different, but it should not be underestimated how much chronic pain can impact a person's life.

In people living with chronic pain:



Chronic pain can affect your ability to take part in social and physical activities. This can impact your relationships with family and friends, as well as your general health and wellbeing.

Chronic pain can also lead to depression, anxiety, and trouble sleeping. Each of these can make your experience of pain worse, and this can eventually lead to a cycle or loop that is difficult to break without support.

It is important that you, and your healthcare team, take time to understand how your pain affects you.

Effective pain management will treat you as a whole person, rather than only focussing on your level of pain.

How to get support with chronic pain

If you have been **experiencing pain for 12 weeks or more**, you should **contact your GP** and ask to discuss this with them.

Your GP may:

- carry out a physical examination
- ask you about your pain and how it is affecting you
- check for any signs of other illnesses

Consider keeping a pain diary to help you prepare for you GP appointment.

Visit <u>our website</u> to learn



Scan the QR code

To support you, your GP may advise you on techniques to help manage your pain levels day-to-day and prescribe you medication that is effective for long-term pain.

Your GP may advise you to try using common painkillers (e.g., paracetamol) for short-term relief or when your pain flares up, but these medications are often not effective for long-term management of chronic pain.

You may be referred by your GP to try different types of physical and psychological therapy. They will also help you consider how to stay active and maintain your general health and wellbeing.

If you continue to face difficulty managing your pain, **ask your GP for a referral** to a pain management service or specialist pain clinic. These are led by teams of healthcare professionals and offer a wider range of therapies to help you develop strategies for managing your pain.

If you have been experiencing pain for 12 weeks or more...

Step 1: Take care of yourself as best you can

Try the following at home to help manage your pain:

- Eating a healthy diet and staying well hydrated
- Keeping active and performing light exercise
- Getting a good night's sleep
- Pacing yourself and making time for relaxation

Step 2: Speak to your GP for more support Your GP may be able to:

- Prescribe you medication to help reduce your pain
- Refer you for physical or psychological therapy
- Refer you to a pain management programme

Step 3: Ask your GP for a referral

If you are continuing to struggle, ask your GP to refer you to a specialist pain clinic or pain management service. These services provide assessment and support from a multi-disciplinary team of healthcare professionals, and available therapies may include:

- Pain-relief injections and nerve blocks
- Radiofrequency ablation
- Spinal cord stimulation
- Drug plant implants

Visit the <u>NHS website</u> to find your nearest pain management centre:



2

3

Scan the QR code

Ways to manage chronic pain

Chronic pain does not often respond to the same pain medication and pain relief therapies that are used to relieve acute pain - and when it does, the relief often lasts for only a short amount of time.

Chronic pain management often combines medical therapies with self-care to maintain and improve your general health and wellbeing - including exercise and physical activity, relaxation, and engaging with others.



Different levels of support for chronic pain

Everyone is affected by pain differently. It is important that you find the right support for you. Your support needs may also change over time as you continue living your life.

It is not always possible to become completely pain-free, and instead the focus may need to be on learning to manage your pain and maintain the best possible quality of life you can.



There are many lifestyle changes, medications, and therapies to consider as you find the right approach to help you reduce your pain and improve your quality of life.

Self-care and self-management

Self-care describes the things you can do each day to take care of yourself and to maintain and improve your own general health and wellbeing. Self-care may involve eating a healthy diet, exercising regularly, sleeping well, and taking some 'me' time. It can reduce stress, improve your energy levels, and boost your self-esteem.

Self-management is more about the things you can do to help manage your pain, and the impact it has on you, when you are at home or going about your daily life.

Self-care is often an important part of self-management, but self-management might also include:

- pacing yourself and your daily activities
- including time for rest as part of making plans
- asking family and friends for support when you need it
- practicing learned skills, such as mindfulness, to help you manage your pain, as well as any challenging thoughts and feelings

Visit www.paintoolkit.org for more ideas.

Medication

Chronic pain may be managed using a combination of painkillers and other medications for long-term pain.

Some of these medications are better known for treating other conditions and you might see them referred to as anti-depressants or anti-epileptics, for example.

Physical therapy

Physical therapy from a trained professional may involve exercises, stretching, and techniques like manipulation, acupund

and techniques like manipulation, acupuncture, or massage to help relieve your pain.

Psychological therapy

You may be referred to see a clinical psychologist to help understand how your pain affects you and how your thoughts, feelings and behaviours have an impact on your pain.

Pain management programmes

These programmes can support you to live with chronic pain by helping you learn more about pain and discover new ways of dealing with the effects caused by it. These programmes are often delivered through group sessions and run over a number of weeks.

Managing an underlying condition

If your pain is being caused by another condition, then treating or managing that condition may be an important part of managing your chronic pain.

This can take place alongside therapies that focus specifically on your pain.

Pain-relief injections and nerve blocks

Medication can be injected close to a nerve or group of nerves to reduce your pain. One or more medications may be used to help reduce inflammation of the nerves and to block pain signals.

Radiofrequency ablation

Radiofrequency ablation (RFA) uses heat on targeted nerves to stop them from sending pain signals to your spinal cord and brain.

Spinal cord stimulation

Spinal cord stimulation (SCS) involves sending small electrical impulses directly to your spinal cord to relieve your pain. These electrical impulses are sent by a medical device that is implanted under your skin.

Restorative neurostimulation

This procedure may be used to help people with chronic mechanical back pain. It is similar to SCS (see above) but in this situation the device sends the impulses to a group of muscles that support your back (multifidus muscles).

Drug-pump implants

A medical device is implanted under your skin and is used to deliver very small quantities of medications directly in to fluid around your spinal cord.



Where to find more information and support

Visit <u>our website</u> to learn more about our work and our services.

We're here for you at every step of your journey.



Scan the QR code or visit www.brainandspine.org.uk

Talk to a nurse on our helpline

Our helpline is run by neuroscience nurses with 70 years of experience between them. It provides a safe space where you can seek support, clarity, and reassurance.

Our specialist nurses can answer your questions, suggest practical next steps, and provide the emotional support you and your loved ones need, when you need it most.

Call us for free on **0808 808 1000** (Mon–Fri, 9am– 4pm), or send an email to <u>helpline@brainandspine.org.uk</u>

Join one of our peer support groups

Our peer support programmes offer safe, welcoming spaces where you can discuss your reality, share advice, and offer mutual support. These programmes include:

- **Neuro Social** online monthly or weekly chat groups led by an experienced staff member or volunteer
- Neuro Carers an online monthly chat group for carers led by an experienced staff member
- Neuro Creatives and Neuro Writing online group sessions that provide a safe space to take part in creative activities

The following websites and organisations may also provide further information and support that can help you manage your pain and connect with others:

- Action on Pain: <u>www.action-on-pain.co.uk</u>
- British Pain Society: <u>www.britishpainsociety.org</u>
- Control Your Pain: <u>www.controlyourpain.co.uk</u>
- Flippin Pain: <u>www.flippinpain.co.uk</u>
- Live Well with Pain: <u>www.livewellwithpain.co.uk</u>
- NHS England: <u>www.nhs.uk/live-well/pain</u>
- NHS Scotland: <u>www.nhsinform.scot/illness-</u> <u>es-and-conditions/brain-nerves-and-spinal-cord/</u> <u>chronic-pain</u>
- Pain Association: <u>www.painassociation.co.uk</u>
- Pain Concern: <u>www.painconcern.org.uk</u>
- PainSupport: <u>www.painsupport.co.uk</u>
- Versus Arthritis: <u>www.versusarthritis.org</u>

A big thank you

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This leaflet was produced as part of a collaboration with Boston Scientific, who provide the NHS with spinal cord stimulation devices. For more information on their range of products, please visit <u>www.controlyourpain.co.uk</u>



Join a community of Changemakers Discover how you can get involved: <u>www.brainandspine.org.uk/neuro</u> -changemakers



Share your experiences with us

Tell us about the challenges you face every day in accessing treatment, care, and support: <u>www.neurolifenow.org</u>

Do you have a question or need more support?

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Give us your feedback and suggestions

We welcome any feedback, comments, or suggestions you may have have about this leaflet. Please send an email with your thoughts to <u>feedback@brainandspine.org.uk</u>

We rely on the generosity of our community to provide free health information and professionally-staffed Neuro Services. We appreciate all donations, big or small. To donate visit: <u>www.brainandspine.org.uk/donate</u>

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